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Journal of Cancer Policy

journal homepage: www.elsevier.com/locate/jcpo

What do we mean by the right to be forgotten? An analysis of the French case study from a lawyer's perspective

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ARTICLE INFO

Keywords:

Cancer
Survivorship
Insurance
Loan insurance
Right to be forgotten
France

ABSTRACT

The return to normal life of cancer survivors is not easy, especially when it comes to taking out insurance. Therefore, France has put in place the Right to be forgotten in order to promote their insurability: it permits every cancer survivor not to declare their cancer 10 years after the end of the active treatment and 5 years if they had cancer under 18. A reference table also defines for different types and stages of cancer, a shorter period of time after which insurers have to apply standard conditions (no extra premium, no exclusion). After presenting the difficulties encountered by former cancer patients, the content and scope of the right to be forgotten will be presented as well as the key aspects of this important reform.

Introduction

Being diagnosed with cancer is no longer the death sentence it used to be [1]. Medical advances in the diagnosis and treatment of cancer explain that there is an increasing number of survivors. In 2012 there are around 12 million cancer survivors diagnosed in the past 5 years and France makes 8% (1 million) of the total population [2]. Cancer survivorship raises new societal challenges, in terms of employment or insurances. Insurances are a major issues faced by cancer survivors as soon as the risk assessment is made from a medical questionnaire, especially for life and health insurances [3]. Even if mortgage life and/or disability insurance are not required by law when taking out a loan home, it is often impossible to borrow money without covering the balance due. In order to solve these problems, one of the flagship measures of 2014–2019 Cancer Plan [4] was the recognition of a “right to be forgotten”, which enables long-term cancer survivors to do not inform insurers that they had cancer [5].

This paper has three main objectives. The first is to provide general background on the insurances' issues faced by cancer survivors (1). The second is to define and explain what does the right to be forgotten mean for cancer survivors (2). The third is to draw conclusions in a pan-European perspective from the analysis of the French case study (3).

1. Insurances' issues faced by cancer survivors

As a mean of protection from uncertainty and financial loss, insurances are widespread used in our modern society. When they cover

the insured person's existence, integrity or health, insurers evaluate all the risks related to the individual. Therefore, candidates fulfill a medical questionnaire and have to answer precisely in order to permit the insurer to assess the risks it assumes” [6]. Intentional reluctance or false declaration made by the insured, when it changes the object of the risk or diminishes the opinion for the insurer, is sanctioned by the nullity of the contract [7]. So it is not without consequences to lie about a cancer one has or one has had.

And yet cancer survivors are attempted to do so, given the difficulties they face in subscribing life and health insurances. When cancer survivors are not discouraged by the very specific questions of the medical form [1], they often face warranty exclusions and/or have to pay significant extra premiums [8]. Insurers can also simply refuse to cover them. For example, during the 2nd EORTC Cancer Survivorship Summit, a famous Opera director, expressed that since the age of 26, when he was diagnosed with Hodgkin's disease, he had been unable to obtain a health insurance whereas he lived in Chicago, London, Munich or Zurich [1]. Cancer survivors experience these difficulties as an unjust double penalty and an additional stigma to cancer. There are only a few qualitative studies on these issues for both adults [9–13] and children [14] since questions about the socio-economic consequences of cancer are not systematically integrated into quality of life studies. It could be interesting to have more data about the socioeconomic consequences of cancer and therefore items about employability and insurability should be systematically integrated into quality of life questionnaires.

Insurances issues are part of the socioeconomic burden of cancer [15]. In order to highlight difficulties faced by cancer survivors in

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<https://doi.org/10.1016/j.jcpo.2018.01.001>

Received 8 October 2017; Accepted 17 January 2018
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matter of insurances, the loan related insurance seems particularly relevant. Indeed, banks systematically require borrower candidates to cover the remaining balance due in the event of payment default and alternatives to insurance such as mortgages are not very widespread in France. In such conditions, cancer survivors, considered as people with an increased health risk, could not easily obtain a loan in order to buy a real estate property because they cannot easily subscribe an insurance to cover it or they have to pay extra premium. A survey carried out among the French population -at the request of patients' rights associations- shows that one in four respondents said they or a relative had been faced with a situation of discrimination against the credit (denial of insurance, additional premium or exclusion of guaranties) [16].

These difficulties aggravate the material living conditions and social wellbeing of cancer survivors. On the contrary, access to insurance for home loans contributes to improve living conditions: for example, in 2015, more than 64% of the French population lived in owner-occupied dwellings and almost 70% of the EU-28 population [17]. Access to real estate property is important in housing conditions at both French and European level. By way of consequence, access to loan insurance is also a major issue and especially for cancer survivors who are mistakenly considered as people with an aggravated health risk. Indeed, the existence of the pathology is taken into account for the evaluation of the risk but not the actual stage of the disease or the fact that it was cured several years ago [18].

2. The French “right to be forgotten”

One of the flagship measures of the former President François Hollande's Cancer Plan was the recognition of the right to be forgotten. Firstly adopted within the framework of the AERAS Convention, it has been voted in the same time into the last French health reform bill. Before analysing the scope and content of the right to be forgotten (Scheme 2), it seems necessary to present its genesis (Scheme 1).

2.1. Genesis

At the instigation of the third Cancer Plan, the right to be forgotten has firstly been adopted within the AERAS conventional framework. The AERAS Convention has been adopted on 6 July 2006 in order to improve the 18 September 2001 Belorgey Convention [19]. In addition to the former three-level risk analysis, a better protection of the borrowers is ensured by the validity of the insurance offer for 3 months and the motivation of the insurance's refusals. A portion of the insurance extra-premium is covered by a solidarity mechanism to reduce the extra-cost of insurance for the poorest.

Regarding conventional institutions, in addition to the monitoring and proposals Committee, there is now a joint mediation Committee.

Renegotiations have taken place and further progress was made on the beginning of 2011: better information of people about the Convention, extension of coverage to disability insurance, alternative guarantees to insurance...

Despite this conventional arrangement, insurers are never required to insure a risk and risk selection cannot be considered as discrimination but should be based on accurate data. The right to be forgotten is based on this idea, taking into account the progress made in the treatment of cancer. Hence, the parties to the AERAS Convention had to reach a consensus before the end of 2015 and define by then, the period beyond which cancer survivors would no longer have to declare it. To help them, the French National Cancer Institute (INCa) provides, for each type of cancer, the scientific data about the recurrence times, probabilities of survival with or without incapacity and probabilities of cures.

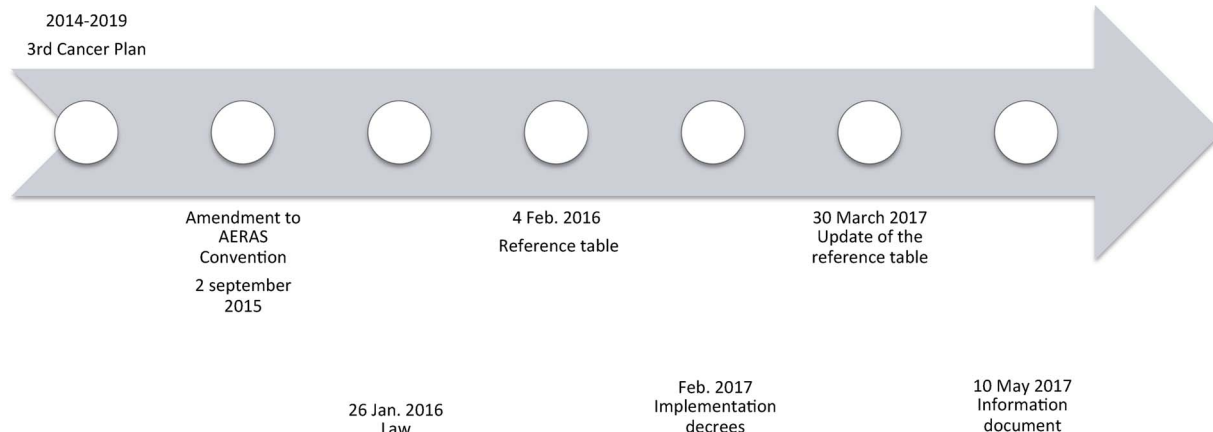
Although negotiations between stakeholders were tough, they resulted in the signing of an amendment to the AREAS Convention on 2 September 2005. The two aspects of the right to be forgotten are then established: on the one hand, the right not to declare old cancer pathology fifteen years after the end of active treatment for people diagnosed after 15 years and five years for people whose cancer was diagnosed before 15 and on the other hand, the adoption of a reference table with specific period of time defined by type of cancer and after which no extra premium or exclusion of warranties can be applied.

In parallel to the conventional negotiations, a major reform of the health system was discussed in parliament. The government introduced an amendment that recognizes the right to be forgotten and should help to its enforcement [20]. Thanks to a very active lobbying work of patients' rights associations, parliamentarians present many other amendments in order to go beyond what has been negotiated within the framework of the AERAS Convention. Thus article 190 of the law was adopted on the 26 January 2016 and defines the two legal mechanisms behind the “right to be forgotten”.

2.2. Object of the two-fold “right to be forgotten”

Indeed, the “right to be forgotten” is a facility of language covering two more specific legal provisions whose both object and scope of application differ.

First, there is a *stricto sensu* right to be forgotten which means that long-term cancer survivors can forget they had cancer when they are filling out the health form to subscribe insurance. In other words, cancer survivors are legally allowed to do not declare their past cancer when the therapeutic protocol has been completed for a certain period of time: 10 years after the end of the active treatment when cancer was diagnosed in adults and 5 years when cancer was diagnosed under 18 [21]. The end of the therapeutic protocol is defined as the end of the



Scheme 1. Chronology/Genesis of the right to be forgotten.

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